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Andrew Symon ***BJM legal column article, March 2017***

A case of Autism, Learning Disabilities, and Refusal of a Planned Caesarean

In November 2016 a London court heard a case concerning a 24-year old whose capacity to consent was being challenged by an NHS Trust. The woman, known as 'CA', who lived in supported accommodation, had presented to the Trust at approximately 30 weeks gestation. However, it was only when she was more than 38 weeks that the NHS Trust applied for a court declaration so that a caesarean could be carried out, if necessary without CA's consent. Court-ordered caesareans are rare, but the established legal doctrine concerning refusal of treatment is well-established: a competent woman can refuse, even if this were to result in her own death or that of her unborn baby (per Butler-Sloss JL in Re MB, [1997]). The crucial question is whether the woman is competent.

The late notification in 'CA' contravened court guidance which stresses the need for early identification of a problem. In cases of pregnancy, this should be no later than four weeks before the expected due date. Late applications run the risk of being dealt with by the out-of-hours judge and without a full public hearing, and with incomplete written evidence. The Official Solicitor, a lawyer known as a 'litigation friend' who is appointed to represent vulnerable individuals, may have inadequate time to prepare the client's case; and there may be insufficient time to arrange for independent expert evidence if this is required (*cf*. Keehan J in NHS Trust 1 v G [2014]).

CA's background history provided further complicating factors. While a small child in Nigeria, she had experienced episodes of 'cutting'. Her mother suggested that superficial abdominal scars had been inflicted to release "bad blood" when CA had been unwell. CA's mother also indicated that CA had undergone some form of Female Genital Mutilation (FGM) as a child. The extent of this was unknown as CA would not agree to an examination. The judge noted that these two episodes held particular significance:

> "For a woman who has undergone the traumatic abdominal incision of the sort described in this case, the prospect of a Caesarean section may well carry risks of psychological or other trauma. On the other hand, for a woman who has

> undergone FGM (of whatever type) there is an increased risk of tearing, blood loss and infection through the process of natural childbirth." (per Baker J @ 14)

The family also claimed that, after they had moved to England, CA had been diagnosed as autistic; however, no medical records were found to confirm this. In the circumstances, her capacity to understand had to be determined. The Mental Capacity Act 2005 (the equivalent Scottish Act is the Adults with Incapacity (Scotland) Act 2000) notes that the court's initial assumption is that capacity is present, so the burden of proof lay with the NHS Trust to establish that CA lacked capacity. It's important to remember that

> "Capacity is both issue-specific and time specific: A person may have capacity in respect of certain matters but not in relation to other matters. Equally, a person may have capacity at one time and not at another." (per Baker J @ 19[3]).

All reasonable steps must be taken to help the relevant person to understand matters. Just because someone makes what may seem an unwise decision does not mean that they lack capacity. In this case CA wanted a home birth with her family present, but with no medical attendants. CA's understanding was that childbirth is straightforward and pain-free (the baby would just 'pop out'), but she also had an aversion to hospitals and medical equipment, and a mistrust of medical personnel. One midwife, 'DW', had made attempts to communicate with CA and to examine her, but with limited success. Care givers have to take reasonable, even exhaustive, steps to try and establish communication channels;

> "… someone is not to be treated as unable to make a decision unless all practicable steps are being taken to help without success." (per Baker J @ 30)

Courts will, if there is time, appoint an independent expert to establish whether the person in question is able to take in information and make decisions. The expert in this case concluded that CA had an IQ of between 60 and 70 and that she was autistic, although there hadn't been time to conduct a full autism assessment. He concluded that while CA was able to communicate her views, she was clearly unable to weigh up information in order to make an informed choice. The judge was persuaded by this evidence, noting that clinical staff had tried their utmost to help CA make these decisions, but that she was simply unable to do so.

The question of autonomy is a crucial one, and it is an extreme stance for a court to rule that a person's expressed wishes about their own treatment can be over-ridden. Having determined that CA lacked capacity, and as governed by the Mental Capacity Act 2005, the judge next had to decide what would be in CA's best interests. While an elective caesarean would allow for a degree of planning and hopefully avoid an emergency situation, it would almost certainly require a general anaesthetic which would probably entail some degree of restraint. The psychological effects of this would be difficult to predict. On the other hand, while a vaginal birth had obvious potential advantages, CA's refusal to allow any monitoring or examination, her apparent lack of understanding that some pain would be involved, and the unknown effects on the existing genital scarring, as well as the possibility that a caesarean might be required in any case, meant that attempting a vaginal birth had significant risks as well.

All in all, this was a very problematic case, not least because of the restricted time available in which to consider matters. The judge concluded, on the balance of the evidence presented, that a planned caesarean section would be in CA's best interests. Despite CA's objections, he was persuaded that the danger of an unplanned caesarean was quite high, and that the psychological risks from this were far greater than from a planned operation. In justifying this decision, the judge stressed that physical restraint must be a last resort. It would have to be by trained personnel, directed by the clinical lead, and necessary to prevent CA from causing immediate harm to herself or others. Crucially, any restraint would have to be fully documented and accounted for.

It can be seen that the courts are unwilling to write a 'blank cheque' to clinical practitioners, in the expectation or belief that they will act appropriately. Any over-ruling of someone's expressed wishes has to be carefully arranged so as to minimise potential harm.

Was this the 'least worst' option, in the circumstances? One way or another a decision had to be made. There is some comfort to be had from knowing that the courts have a presumption of capacity; that only in exceptional circumstances will this be over-ridden; and that when this happens the courts will try to ensure that the relevant person's best interests are safeguarded.

As it happens, a planned caesarean section was performed with apparently minimal restraint, and a baby, lying in the breech position was delivered. CA was found to be significantly anaemic, and was transfused 2.5 litres of blood.

References

NHS Trust 1 v G: Practice Note [2014] EWCOP 30

Re CA (Natural Delivery or Caesarean Section) [2016] EWCOP 51

Re MB (Adult, Medical Treatment) [1997] 38 BMLR 175 CA